

VISTAS

A NEWSLETTER OF THE ARIZONA GOVERNOR'S COUNCIL
ON SPINAL AND HEAD INJURIES

Winter 1999

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Saluting Our Partners



*Clockwise from top:
Chrystal Snyder,
Annette Zaccari,
Gary Venjohn,
Joseph Corrigan*

Welcome to the second issue of *Vistas*, the newsletter of the Arizona Governor's Council on Spinal and Head Injury.

In this issue we highlight the work of two of our key partners, the Brain Injury Association of Arizona and the Arizona United Spinal Cord Injury Association. Both organizations fill a tremendously important role in the continuum of

services for individuals with brain and spinal cord injuries as well as for their families, friends and the professionals who work with them.

What do the Associations do? Many things—but in a nutshell, we'd say that they serve as the authentic voice of the community. They reach out to those we serve; they provide vital feedback to the Council on a host of grassroots issues; they partner with us in our efforts to make information available to the public.

While both Associations are statewide in their focus, they also bring us exper-

tise on a national level. For example, the Brain Injury Association of Arizona recently hosted the National Brain Injury Association's annual training conference on Information and Resources. The Arizona United Spinal Cord Injury Association will be the next host of the National Spinal Cord Injury Association's Annual Education Conference. These connections to national organizations broaden our perspective and help us learn from the successes (and sometimes the mistakes) of other states.

Both organizations run, largely, on volunteer energy. While both have talented professional staff, their success is due in great measure to the commitment and the caring of the many individuals who give their time, energy and resources.

We believe that, working together, the Council and the Associations represent what's best about public/private partnerships. We appreciate their efforts, and we're proud to salute them in this issue of *Vistas*.

— Chrystal Snyder

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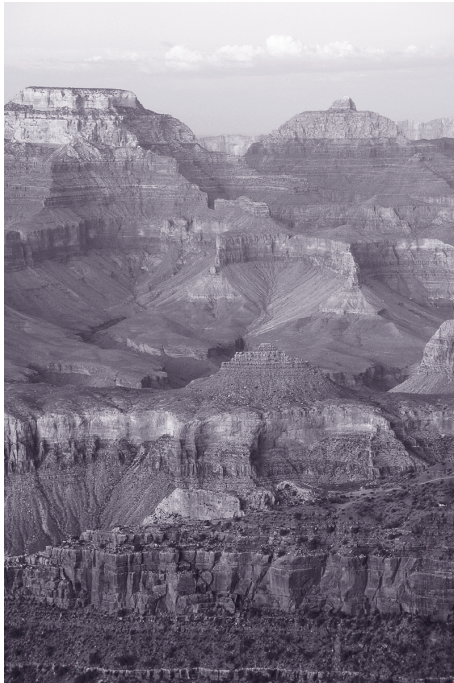
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Brain Injury Association of Arizona Charts a New Course

“WE’RE
FOCUSING
ON
VISIBILITY,
AWARENESS
AND
RESOURCES.”



The Brain Injury Association of Arizona (BIA of AZ) has served individuals with traumatic brain injury and their families for 16 years. This summer, the Association hired its first Executive Director, Linda Weinberg. Recently, Vistas spoke with Ms. Weinberg about her goals for the Association.

Vistas: The Brain Injury Association of Arizona has been active for nearly two decades as a volunteer organization. What prompted the decision to hire an Executive Director?

Linda Weinberg: The Association has an incredibly dedicated Board of Directors. Volunteers established the Association; they present at conferences, they advocate for funding. However, the Association has grown to the point where the Board needs a full-time staff person to implement its ideas and programs. That’s where I come in.

Vistas: What kind of background do you bring to the position?

LW: I have a strong background in behavioral health. I’ve worked as a planner and negotiated and monitored behavioral health contracts. I’ve also done a

lot of grant writing, and I served as Executive Director of an agency that assisted homeless families. I received a grant from the National Institute of Mental Health to complete my Masters in Social Work degree from ASU.

Vistas: What are the primary areas of focus for the Association in the upcoming year?

LW: We’re focusing on three areas—visibility, awareness, and resources.

Vistas: Why visibility?

LW: While the Board has been incredibly active over the years, it hasn’t always been real visible—so people who need our assistance the most may not know we’re here. We also need to raise our visibility because it will help us in soliciting funding. As a first step, we’re establishing an office in space donated by one of our board members.

Vistas: How does the Association plan to raise awareness?

Every 15 seconds someone sustains a head injury, and 5.3 million people—about 2% of the population—are living with head injuries. Yet one of the most difficult aspects of a head injury is that often the damage is not visible—so people aren’t aware of the extent of the injury, and misdiagnosis may occur.

We need to educate professionals about injury prevention and about the lasting

effects of a head injury. We also need to establish educational programs in the schools. Just as we teach children about fire safety and "stranger danger," we also need to raise their awareness about preventing head injuries.

Vistas: What are you planning in the area of resources?

LW: We want to be the focal point in the community for prevention, education, and advocacy efforts. Currently, we have information lines in Phoenix and Tucson. Our next step will be to establish a toll-free number so we can assist individuals statewide.

Vistas: How can people contact the BIA of AZ?

LW: Call us! Our phone number in Phoenix is (602) 952-2449 and in Tucson, (520) 747-7140.



Clinic Helps Ease School Re-entry

"Children who return to school after a traumatic brain injury face significant challenges," says Dr. George Prigatano, director of the Clinical Neuropsychology Department at Barrow Neurological Institute. "So do their parents, teachers and peers."

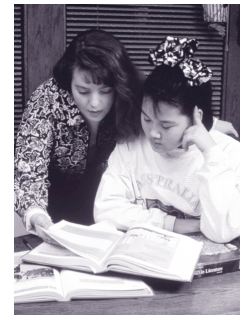
Yet little guidance is currently available for professionals and family members as they help children negotiate these challenges, says Dr. Prigatano. To better understand the difficulties of school re-entry, Dr. Prigatano conducted an intensive summer clinic for children with traumatic brain injury. The clinic took place at Barrow Neurological Institute in Phoenix.

Participants in the unique 6-week program were children between the ages of 7 and 8 who had sustained traumatic brain injuries. All had been determined to be ready to return to school, but had experienced difficulties in the school environment.

"Academically, students struggled in the areas of language, memory, and concentration," explains Dr. Prigatano. "They also had problems understanding appropriate classroom behavior and cooperating with others."

A major goal of the study is to provide schools with better information on working with children with brain injuries, particularly as they re-enter the school setting.

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A MAJOR
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INFORMATION.

New Spinal Cord Injury Association Tackles a Big Job

“PEOPLE
WITH A
SPINAL CORD
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A BETTER
TOMORROW.”

On April 1, 1999, the Arizona United Spinal Cord Injury Association (AUSCIA) opened for business with a grant from the Governor’s Council on Spinal and Head Injuries. But for Paul Mortensen, Executive Director, the effort really began on September 23, 1997.

That’s the day his 23-year-old daughter suffered a spinal cord injury. Up to that point, Mortensen says, “I really didn’t know what a spinal cord injury was.”

His reaction was not unusual. “Spinal cord injuries happen so suddenly and so unexpectedly that the trauma takes the family and the injured person totally by surprise,” he says. And that’s also the reason there is so much work to be done by the newly formed association.

with spinal cord injuries and their families. Its agenda is ambitious.

Peer and family support groups, education of consumers, families and professionals, and a link to resources are just a few of its areas of concern.

The Association is setting up an information and referral library, not only in hard copy but also on the Internet. Support groups for adult consumers, for family members and for young people 8-18, are now meeting on a monthly basis with neuropsychologist Stewart Thomas. An Early Intervention Program designed to work with people during the first 90 days after an injury is in place. The Association is also making a special effort to focus on the prevention of spinal cord injury by supporting programs that teach safe driving and recreation habits.

To describe the goals of the Association, Mortensen quotes the organization’s new theme: “Wheels Toward a Dream,” a paraphrase of an old ragtime duet. It means, Mortensen says, that “people with a spinal cord injury have a right to dream of a better tomorrow, to dream of and hope for the maximum possible physical, psychological and social recovery.”

The Association has already begun to take major strides in helping people achieve that dream. To contact AUSCIA, please call (602) 239-5929.



The Arizona United Spinal Cord Injury Association wants to provide information and guidelines for people

The Art of Isabelle Jackson: Inspiring, Serene and Hauntingly Beautiful

“G oldie” looks over her bare left shoulder, strands of hair falling across her face, a butterfly tattooed on her back. She gazes right past you, as if you were not there, as if there were something far more important happening elsewhere.

This lovely, mysterious image is the work of Isabelle Jackson, a Navajo artist from Keams Canyon. For more than 20 years, she has painted with a brush held in her mouth. Her career began after a spinal cord injury received in an automobile accident at age 17 left her unable to use her hands.

Isabelle started to paint soon after she left the hospital. The young man who eventually became her husband and Carolyn Mitchell, her social worker, encouraged her to do so. Both are still encouraging her, although today many know the work of Isabelle Jackson.

Isabelle works in watercolor, oil, and pen and ink. Most of the images come from her imagination, although all have roots in Navajo culture: maidens with shy smiles, a young boy herding sheep, a hogan covered with snow, the Madonna and child stylized to reflect the Navajo vision.



her work. Carolyn Mitchell, now a close friend, says that these images “are reflective of Isabelle herself.” She knows who she is and what she can do, and she is strong and beautiful.

Isabelle Jackson, the artist, is also a wife and mother of a 15- year-old son. She is a member of the International Foot and Mouth Artists Organization.

Isabelle Jackson’s work is available through AUSCIA. Please call (602) 239-5929 for more information.



MOST OF
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ROOTS IN
NAVAJO
CULTURE.

A thread of introspection, calm assurance and private thoughts run through

PREVENTION

The Banner Wheelchair Suns. Score One for SCI Prevention.

Since 1988, they've been playing wheelchair basketball to dramatize that people with disabilities have abilities – significant and impressive athletic abilities. Now, the Banner Wheelchair Suns are taking that message to schools and expanding it to include a powerful prevention message as well.

Former Council president Gary Venjohn, Access Employment Coordinator at Arizona State University and also

the coach of Banner Wheelchair Suns, says that the team is doing presentations in schools because the teenage audience is in need of a glimpse of reality right now. (The incidence of teenagers, under 18 arrested for DUI, notes Gary, has doubled in the last few years!)

“Before they get their driver’s license,” Venjohn says, “teenagers need to hear about the dangers of drinking and driving. Someone sitting in a wheelchair, someone who’s an athlete, can deliver that

‘drive safe’ message in a powerful way.”

The Banner Wheelchair Suns are sponsored by the Phoenix Suns, Banner Health Care and America West Airlines. The team plays as many as 30 games a season as part of the 200-team National

Wheelchair Basketball Association. (It’s actually an international league, with teams in Latin America, too). They play from coast to coast, from Miami to San Diego, and last year, the 15-member Wheelchair Suns came within 6 points of making “The Final Four” in Chicago.

“Wheelchair basketball is a tough, competitive, demanding game,” notes Venjohn. “We play a full-court fast-break offense, switch to half court if necessary, play zone and triangle zone defenses as well as man-to-man. Our guys are in shape.”

Gary points out that all basketball players need to control the ball and their body; wheelchair players need to control the ball, their body (which often does not respond as they’d like) *and* the chair as well. No small task.

Even with those demands, good teams, like the Wheelchair Suns, can average 70-80 points during a regulation NCAA-level 40-minute game!

The Banner Wheelchair Suns are scoring big points for people with disabilities, and doing their best, as well, to prevent others from being injured. Go, team, go!



RESOURCE REVIEW

Toy Guide Gives Santa a Helping Hand

(Editor's Note: In each issue of *Vistas*, we spotlight a resource—a book, tape, Web site or other publication—that may be helpful to people with spinal cord or brain injuries or to their families and friends. If you have any suggestions for resources to be featured in this column, please let us know and we'll try to spotlight them in future issues.)

With the holiday season upon us, Santas in every corner of the state are making their lists and checking them twice. If Santa's list includes a child with a brain or spinal cord injury, he may want to consult the *Toy Guide for Differently-Abled Kids*.

This colorful catalog is a joint effort of Toys 'R' Us, the National Parent Network on Disabilities, and the National Lekotek Center, an organization dedicated to bringing families of children with disabilities together to play, explore and just have fun.

The catalog presents 27 pages of toys for children of all ages. Each toy is paired with a series of symbols, representing the developmental skills or senses that it enhances: auditory, language, visual, tactile, gross motor, fine motor, social skills, self-esteem, creativity and thinking.

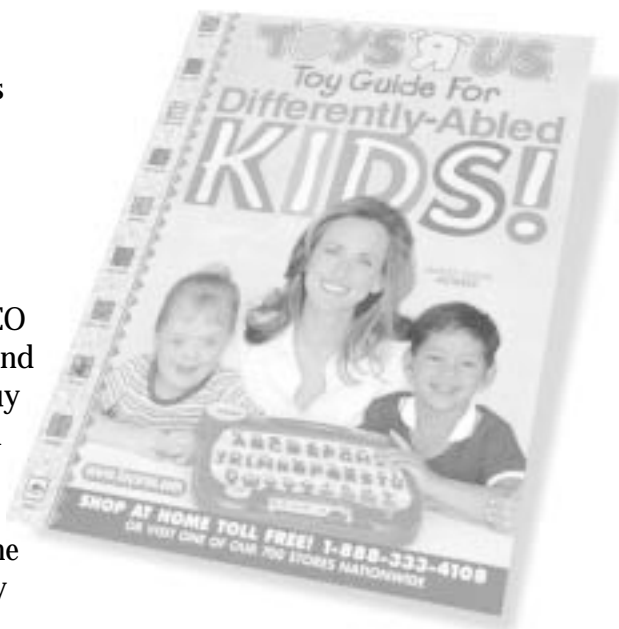
The goal, according to Toys 'R' Us CEO Robert Nakasone, is to help parents and others by "making it a lot easier to buy the right toy for any differently-abled child."

The catalog recognizes that finding the right match between a child and a toy

can be challenging. It offers guidance to parents and others on what to look for in evaluating a toy's suitability for a particular child—for example, method of activation, adjustability, opportunities for success, and potential for interaction.

Actress Marlee Matlin, who is deaf, appears on the catalog's cover and stresses the importance of finding the right toys in her introduction. "Children...who have disabilities have the same dreams as all children," she writes. "Toys are a child's tools to help them build their dreams and create their future."

Now in its 6th edition, the catalog is available free of charge at the customer service desk at Toys 'R' Us stores nationwide. It's also available by calling toll-free, 1-800-732-3298 or 1-888-859-8011 (TDD/TTY).



Available from the Governor's Council

Visit our Web site at www.azrsa.org/head&spine

The Council donates materials to these libraries and organizations:

Flagstaff Public Library
(520) 779-7672

Prescott Public Library
(520) 445-8110, ext. 3

Yuma Public Library
(520) 782-1871, ext. 124

Phoenix:

Emily Anderson Center
(602) 239-6902

Maricopa County Library
(602) 506-5763

Phoenix Public Library
(602) 261-8690

Raising Special Kids
(602) 242-4366

Tucson:

Pilot Parents Partnership
(520) 324-3150

Ronald McDonald House
(520) 326-9003

Tucson-Pima Public Library
(520) 791-4393

Brain Injury Resource Centers (BIRCs) are interactive multimedia programs that provide information on brain injury. You'll find a BIRC kiosk located at these hospitals:

Flagstaff Medical Center
1st Floor West, Outpatient Therapy

St. Joseph's Hospital
Phoenix
1st Floor, Inpatient Neuro Rehab

Tucson Medical Center
Surgical Waiting Room

For more information, call:

Brain Injury Assoc. of Arizona
Phoenix: (602) 952-2449

Tucson: (520) 747-7140

AZ United Spinal Cord Injury Assoc.
(602) 239-5929

School Re-entry Continued from Page 3...

Each day at the clinic featured a variety of rehabilitation and educational activities. These included cognitive retraining, academic assistance, physical activity, quiet time, and group discussion.

A staff of four psychologists, an occupational therapist, and a special educator worked with the children, individually and in small groups.

Dr. Prigatano believes the program benefited the students as well as parents and professionals. He plans to conduct a similar clinic next summer and, if funding allows, during the school year's winter break.

For more information on the clinic, call Barrow Neurological Institute, (602) 406-3671.

**Do you know someone who would like to be added to our mailing list?
Call (602) 863-0484 or e-mail: mnshcolnik@aol.com**

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*This material is available in alternative
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Arizona Relay Service.*

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